Rooted in Research

SARRC's Colonel Harland D. Sanders Center for Autism Studies conducts critical research to support the 1 in 88 children impacted by autism today.

Page 18
Proudly Supports SARRC in its Research and Assistance to Individuals and Families Affected by Autism.

LIVES CONNECTED
Unlocking the Science Behind Autism  
Thanks to a $1 million grant from the Colonel Harland D. Sanders Foundation, SARRC’s new Sanders Research Center sets off in its inaugural year by carving new paths to therapeutic and medical discoveries.

Reaching Across the State  
SARRC’s Remote Program enables families living outside the Phoenix Metro area to access training and services thanks to the Gila River Indian Community.

Early Achievers  
Bodie Bernosky and Levi Abbitt, students in the SARRC Community School, make great progress thanks to the preschool program’s highly individualized approach and low student-teacher ratio.

Job Well Done  
29-year-old Frank Ortiz, a client in SARRC’s Employment Services program, achieves what many adults with autism find very challenging – successful employment.

A Wider Reach  
SARRC’s Education & Training team provides instruction about evidence-based intervention techniques based on the principles of applied behavior analysis (ABA) to educators across the country, including the Arkansas Department of Special Education and Hawaii Department of Education.

Walk Now  
The 2011 Walk Now for Autism Speaks shattered records and the 2012 Walk is poised to be as successful.
Your Thoughts

Ending the Year on a High Note

Thank you SARRC for everything you have done for us during the past year. Your staff members’ continued support, guidance and enthusiasm have made this an incredible year for us. We reached highs that we previously thought were impossible, and a low (compliments of our insurance company) that we could have only survived with your help.

We just shared our last dinner of the year with Colton eating cheese tortellini, corn on the cob, and hearing him spontaneously say, “I love you!” It doesn’t get much better than that!

Jenn Lemaster
Paradise Valley, AZ

A Poem Inspired by a Special Brother

(Editor’s note: This poem was written by a 7th grade student who has an older brother with autism. It was part of an assignment to write a poem in the style of Shel Silverstein’s “If” poem. The family recently shared it with SARRC.

If you can live your life, knowing you’re different, and know people talk about you behind your back.
If you can ignore what people say about you, and if you would rather be alone.
If you have trouble expressing who you are through words Or you just can’t write down how brilliant you really are.
If you have trouble knowing what others say, and would rather not know.
If you’re not afraid to show who you are and express yourself through music.
If you can make others cry, and not know why.
If you go through phases of likes and dislikes
If you talk, others don’t understand, but you make them smile anyways.
If you could not even hurt a fly.
If you inspire others to work harder, and make a whole team work together.
If you’re scared to impress your younger brother, and would never cough a lie.
If you can show love, and try to make every day the same.
If you make every one around you feel good about themselves, you are my brother Jesse.

Devin Bowen
Gilbert, AZ
After nearly two decades of living with autism, Matt continues to surprise and amaze us with what he knows — and what we don't. In recent months, we learned he can recite every word of every Dr. Seuss book, sing virtually any Beatles song and identify the various production companies of all his favorite films. Add this to his ability to solve triple-digit multiplication problems in his head, serve as our human GPS system to his favorite places and attract the cute girls at school who kindly support him, and one can understand how Matt’s autism often cloaks his many gifts and abilities.

Even though Matt has entered adulthood and is nearly 21, that doesn't stop our diligence in helping him learn and grow. It also doesn't end our incessant worries. We're just dealing with a new set of challenges.

Recently published longitudinal studies cite the high levels of stress associated with parenting children with autism at every age. Reports also warn of an imminent cliff for this generation of young adults as the school bus stops coming and they are faced with a disjointed adult service provider network, age-related medical issues, developmental regression and an aging parent population with fewer family and economic supports. Also consider the prior generation of individuals with autism who didn't benefit from the IDEA, ADA, federal protections, early diagnosis and early intervention.

SARRC is dedicated to helping individuals living with autism live healthier and happier lives. We've been preparing our families and community with early intervention, educator outreach and parent empowerment initiatives since 1997, while advancing discoveries. SARRC has also been maturing through the creation of a robust Vocational & Life Skills Academy. This community-based program has been setting the stage for the introduction of a model residential program that will be breaking ground next year, empowered through a private/public/nonprofit collaboration. You'll be learning more about this major initiative in the year ahead.

SARRC is committed to ensuring adults living with autism and Asperger’s have the greatest opportunities to succeed and enjoy the benefits of a home, job, community support and friends. To that end, SARRC is also partnering with national autism organizations across the country to increase awareness and appreciation for the challenges before us, transform promising practices into best practices and address critical public-policy concerns.

We know kids with autism continue to learn at every age and so do we as parents. As Matt’s parents, we’re still working hard to help him learn how to untie his shoes before slipping them on his feet, adjust the water temperature in the shower, remember to take off his sweatshirt in the heat of the day, eat new foods and tell us how he’s feeling or where it hurts.

We also know it’s our responsibility to educate the community at every opportunity. Thank you for enabling SARRC to build a strong foundation and branch out in new and innovative ways to support individuals with autism and their families throughout their lifetimes.

With gratitude,

Denise D. Resnik
SARRC Co-founder and Matthew’s Mom
Stronger together

Building the future means doing one thing everyday – surpassing expectations. We proudly salute the staff and volunteers of SARRC, who make a world of difference in the lives of children with autism and their families.

Not Everything We Do Can Be Measured In Kilowatts.

In addition to making clean, renewable energy a reality, APS is proud to support hundreds of organizations like the Southwest Autism Research & Resource Center that improve the health, education, arts and economy of Arizona—now and for generations to come.

To learn more about APS’s commitment to building a better Arizona, visit aps.com.
Together, we are creating a better world for individuals and families living with autism. It’s what we do every day at SARRC. And it’s a privilege. It’s made possible because of a strong foundation, rooted in research and in this community. The children, teens, adults and families we serve, and our supporters have all played a major role in nourishing and strengthening our “roots,” over the last 15 years, and it’s empowering our continued growth.

SARRC recently opened the Colonel Harland D. Sanders Center for Autism Studies, providing a greater impact on autism by engaging in more pharmaceutical, therapeutic and diagnostic research, while facilitating studies on the ever-increasing number of adults living with autism. We continue to expand our pharmaceutical trials and are one of the top recruitment sites in the country (see page 18).

We have also expanded our reach beyond Arizona in the areas of education and training. Through SARRC’s newest contract with Hawaii’s Department of Education, we’re helping to build capacity and develop centers of excellence in schools for students with autism spectrum and related disorders (see page 28). SARRC’s preschool is also receiving more national attention. The Centers for Medicare and Medicaid Services (CMS) recognized SARRC’s Community School as one of the top, most promising programs in the country for children with ASDs.

We are obsessed with results. In 2011, SARRC served 1,200 children, youth and adults; 5,000 parents and family members; and 3,700 education and medical professionals. Children are graduating from SARRC’s pre-K classroom and thriving in typical kindergarten classrooms with little to no support from aides – a triumph for our families and significant savings for our public schools (see page 24). We are also making substantial strides with our adult programs. More than 65 percent of SARRC’s clients are gainfully employed in full- and part-time positions (read about Frank’s story on page 26); compared to 10 percent nationally.

Even in these trying economic times, SARRC has stayed strong and become less reliant on state and federal funding, which now represents less than 3 percent of annual revenues. Through corporate partnerships we’re also branching out and pursuing earned income ventures to achieve social change on a grander scale (see page 27). This enhances our social agenda of awareness and allows us to further diversify our revenues through innovation, an entrepreneurial spirit and commitment to create lasting social change.

To continue achieving results, we stay true to our mission and remain grateful to our extraordinary team and generous community of supporters, who share our passion for serving those impacted by autism.

With gratitude,

Jeri Kendle
SARRC President
In Brief

Children’s Book, I’m Here, Benefits SARRC

Inspired by SARRC, New York Times best-selling author and illustrator Peter H. Reynolds recently released his newest “storybook for all ages” called I’m Here. The book is based on the short animated film, produced by Reynolds and his Boston-based educational media firm, FableVision, in collaboration with SARRC. Written about a boy on the autism spectrum, I’m Here features a strong anti-bullying message and reminds us that all children — and the friendships they make — can take flight in unexpected ways. A portion of proceeds from book sales benefit SARRC.

I’m Here and SARRC’s FRIEND® (Fostering Relationships in Early Network Development) Program are helping bridge understanding and empower teachers to facilitate relationships between children with autism and other special needs with their typically developing peers. SARRC, Peter H. Reynolds and FableVision also teamed up with well-known author, 2010 Presidential Medal of Freedom recipient and Holocaust survivor Gerda Weissmann Klein to produce Wings of Epoh, which elevates children’s understanding and respect for those who are different and the courage it takes to live with differences. Educator activity guides are also available and support the use of the books and films in the classrooms. To learn more or make your purchase, visit www.autismcenter.org and www.fablevisionlearning.com/imhere.

Another ‘Beauty of a Bonzer’

SARRC extends a big thank you to Matt McMahon for his leadership and production of the 11th Annual Beauty of a Bonzer (Australian for “great party”), sponsored by Outback Steakhouse and Bud Light. The Front Men provided the entertainment and helped raise more than $13,000 for SARRC.

Community School Families Enjoy Pumpkin Patch

Sponsored by Pearson & Company, the Desert Botanical Garden’s Pumpkin Patch was opened free of charge to children with special needs across the Valley. Students from SARRC’s Community School and their families were able to wander among the pumpkins, while listening to the sounds of a bluegrass band. They were also treated to a petting zoo, hayride, carnival games and face painting!

Four Seasons Helps Families Create Gingerbread Village

In late November, nearly 30 families from SARRC’s Community School took a trip to the Four Seasons Resort in Scottsdale to decorate their own gingerbread houses. Pastry Chef Lance Whipple was on hand to provide expert guidance for their creations. The houses were integrated into a display with donations benefitting SARRC.
Arizona Cardinals Support ThinkAsperger's®

The Arizona Cardinals know how to tailgate and they threw a great tailgate party for more than 100 families to support SARRC’s ThinkAsperger’s® program. Larry Fitzgerald, star wide receiver, generously donated his time to star in a public service announcement promoting the event.

Perkins Coie Sponsors Summer Camp

The 2011 teen summer camp at Whispering Hope Ranch provided teens with autism spectrum disorders and their typical peers the opportunity to escape the heat and participate in a variety of camp activities designed to build social skills and self-esteem in a fun, relaxing and safe environment. SARRC extends its thanks to the law firm of Perkins Coie for their sponsorship. For more information about the 2012 summer camp, contact Erica Skepnek at ESkepnek@autismcenter.org.

SARRC Scores with Golf-related Fundraisers

The Sky Harbor HMS Host Invitational was held at The Camelback Golf Club where the tournament began 25 years ago. For the first time in its history, the tournament featured a women’s golf clinic in which Denise D. Resnik, SARRC’s co-founder, was an enthusiastic participant. The tournament has been raising funds for SARRC since 2006.

The Sixth Annual Sutton’s Strokes for Little Folks golf tournament benefitting SARRC was held at the Arizona Grand Resort in 2011 and drew a record number of golfers. The tournament is sponsored by Darren Sutton, the “voice of the Arizona Diamondbacks.” The seventh annual tournament is being held on May 10, 2012. For additional information and to register, please visit www.suttongolf.org.

Jason Strack, president of Platinum Approach, has created another fabulous golf calendar featuring some of Arizona’s premier golf courses. The calendar includes a discount golf card offering 50 percent off each sponsored course. Once again, Strack is generously allowing 100 percent of all calendar sales through SARRC to remain at SARRC. To purchase a calendar, please call us at (602) 340-8717, ext. 1188.

Education is a responsibility we all share.

SCF Arizona, the state’s leading workers’ comp insurance provider, educates employers and workers on staying safe. Let us show you how. It’s simple: Safe businesses save money. Visit scfaz.com to learn more.
Thanks to donations from Cox employees, customers and community partners, Cox Charities was able to give a total of $545,000 to 99 Arizona nonprofits this year to support youth and education programs. Since its inception, Cox Charities has awarded more than $3.4 million in grants statewide. Together, we can make a difference.

‘Magic on Main’ Benefits SARRC

Pearson & Company celebrated 20 years on Main Street in Scottsdale by hosting an open house featuring items from several of SARRC’s programs including CulinaryWorks®, Autism Artisans® and Humana GardenWorks®. Pearson and Company, a full-service plantscape design company, is a longstanding supporter and generously donated 10 percent of their sales that evening to SARRC.
SARRC Among ‘Best Places to Work’

SARRC has been named among the 2011 Best Places to Work in the Valley by the Phoenix Business Journal. Selection was based on staff survey results. SARRC staff members know the work they do here everyday is more than just a job and we are so proud of them.

Legislative Leaders Treated to St. Patrick’s Day Lunch

For the third year in a row, SARRC invited Arizona’s elected leaders to a St. Patrick’s Day lunch on the House Lawn at the Capitol Building. Led by board chair, Howard Sobelman, SARRC shared news about the innovative remote telemedicine program that allows families affected by autism living in remote areas of Arizona access to ongoing treatment without having to leave their homes. Matt McMahon’s Outback Steakhouse team, which includes valued employees with ASDs, served a traditional lunch of corned beef and cabbage.

10-year-old Donor Brings in the Bacon

Over the years, SARRC has received donations from some very clever donors who raised funds through birthday parties, school drives, a Tootsie Roll Drive (Knights of Columbus) and even a women’s prison (Perryville San Carlos Unit) that sells ice cream and yogurt to support SARRC.

But 10-year-old Baylor Banning ranks as the most unique donor. Baylor is a graduate of SARRC’s JumpStart Early Intervention Program who came to SARRC with his parents, Nicole and Lee, when he was just 3-years-old.

How is his donation unique? Baylor raised a pig from birth and sold this magnificent animal at the Maricopa County Fair then took his earnings and very proudly walked into SARRC with a check.

According to Baylor’s mom, “His dad and I are just amazed and proud of him. He always has a smile on his face and he’s just happy to participate! This year he is showing two pigs at the Maricopa County Fair.”
Sheri Dollin, M.Ed
Education and Training Program Manager

Q. What is your role at SARRC?
A: At SARRC, I develop and implement knowledge- and skill-based education and training activities. Instrumental in the creation of the FRIEND® program, I provide trainings and work on projects related to empowering children at school to understand and accept their peers with autism. My role also includes supporting local and national outreach efforts for SARRC. And more recently, I have expanded our work to provide capacity building through professional development and programming for the Hawaii Department of Education.

Q. What do you like most about your job?
A: Fifteen years ago, when Denise Resnik asked me to get involved with SARRC, I knew this little organization was destined to impact the community affected by autism in big ways — I wanted to be a part of that. SARRC has always stayed true to its vision and I am proud of what we have accomplished — and what is still to come. Our commitment to programs and services that change lives for the better is what I like most about our organization. SARRC represents a community of dedicated, hard-working people who really care about making a difference so autism is well understood, accepted and supported.
Donors Who Make a Difference

Organization: Sanderson Ford Lincoln
www.sandersonford.com

FOR THE 10TH CONSECUTIVE YEAR, Sanderson Ford Lincoln hosted Operation Santa Claus and our community came together in support of local nonprofits, including SARRC, by donating toys, clothing and food. Sponsored by The UPS Store, Bonneville Media, CBS Radio and ABC 15, this year’s event broke all records, collecting 30,000 pounds of food items to benefit Arizona families and raising $58,000 in a first-ever telethon broadcast on ABC 15. Thanks to Sanderson Ford, SARRC was able to provide a very happy holiday for 123 of our families.

Organization: Safeway
www.safeway.com

NEARLY 100 SAFeway volunteers recently teamed with Rebuilding Together to beautify SARRC’s Vocational & Life Skills Academy campus. The Safeway volunteers, together with SARRC clients and staff members, painted murals and installed a hydroponic garden system, composting bins and an enormous shade sail creating a pleasant outdoor classroom space. One of the favorite projects of the day was installing vermiculture (worm composting) bins... who doesn’t like playing with worms? Thanks to Safeway for providing the vital elements that have allowed SARRC’s GardenWorks® program to flourish.

On a Mission to Serve

TriWest is proud to sponsor the Southwest Autism Research and Resource Center’s 14th Annual Community Breakfast.

We are privileged to serve those who serve by providing access to high-quality health care and superior customer service to military families in Arizona and across the TRICARE West Region.

TriWest
whatever it takes!
TriWest.com ★ facebook.com/TriWest ★ twitter.com/TriWest
Questions about participating in pharmaceutical research trials need to be carefully considered and answered so you can make the right decision for yourself, your children and your family. Listed below are frequently asked questions at SARRC. We hope the answers provide some basic understanding to help you make an informed decision.

Why should I participate in a pharmaceutical trial?
Progress is made through research, which cannot be advanced without participants. All FDA-approved medications are investigated thoroughly. Without pharmaceutical trials, we would not have effective medications. Consider participating for the good of your family and the greater good too!

Is it safe for my child to participate?
Once a participant is in a trial, s/he is monitored closely by the staff at SARRC and has regular contact with our study physician. We ask questions about his/her general health and well-being, and closely monitor results from exams and lab reports. The oversight doesn’t stop there. An additional level of review is conducted by professionals associated with the pharmaceutical company sponsoring the study. The participants’ health and safety is everyone’s primary concern.

Will a drug cure autism?
No. Most medications target problems that are experienced by individuals with autism, such as irritability, aggression or gastrointestinal issues. More recently studies are targeting core symptoms like social communication or repetitive behaviors. No one assumes these medications will magically eliminate a problem, but even small improvements can represent significant progress and improve the quality of life for the individual with autism and the family.

Will my child definitely get the medication?
All studies are designed differently. The best studies are double-blind, placebo-controlled. That means that some get the drug, some don’t, and no one in the family or at SARRC knows who is who. This design protects against what is known as the placebo effect, which is perceived progress as result of merely participating in a trial. There are problems caused by placebo effects and this design helps us identify only genuine progress. Many of these trials also have an open-label component, which means that after the blind study, all subjects are given an opportunity to be on the drug. Of course, careful monitoring continues during that part of the study too. The study coordinator at SARRC can discuss the design and help you decide if it is right for you.
Comprender los ensayos farmacéuticos

Preguntas acerca de la participación en ensayos de investigación farmacéuticos, deben ser cuidadosamente consideradas y respondidas para que pueda tomar la decisión correcta para usted, sus hijos y su familia. A continuación se encuentran algunas de las preguntas más frecuentes en SARRC. Esperamos que las respuestas le permitan formar una idea básica para ayudarle a tomar una decisión correcta.

¿Por qué debo participar en un ensayo farmacéutico?
Progresos se hacen mediante la investigación, que no podría ser avanzado sin participantes. Todos los medicamentos se investigan a fondo y son aprobados por la FDA. Sin pruebas farmacéuticas, no tendríamos medicamentos eficaces. Considere la posibilidad de participar por el bien de su familia y el bien también!

¿Es seguro para mi hijo/a participar?
Una vez que un participante participa en un ensayo, él / ella es monitoreado de cerca por el personal de SARRC y tiene contacto regular con nuestro médico. Le hacemos preguntas acerca de la salud y el bienestar general, y vigilamos de cerca los resultados de los exámenes e informes de laboratorio. La vigilancia no se detiene allí. Un nivel adicional de revisión es realizada por profesionales relacionados con la empresa farmacéutica que patrocina el estudio. La salud de los participantes y la seguridad es la principal preocupación de todos.

¿Hay un medicamento para curar el autismo?
No. La mayoría de medicamentos se dirigen a los problemas que experimentan las personas con autismo, tales como problemas de irritabilidad, agresividad o gastrointestinal. Más recientemente, los estudios se dirigen a los síntomas centrales como la comunicación social o conductas repetitivas. Nadie espera que estos medicamentos eliminen el problema por arte de magia, pero incluso pequeñas mejorías pueden representar un progreso significativo y mejorar la calidad de vida de la persona con autismo y la familia.

¿Va a estar mi niño definitivamente en medicamentos?
Todos los estudios están diseñados de manera diferente. Los mejores estudios son doble ciego, controlado con placebo. Eso significa que a algunos se les da la droga, y a algunos no se les da, y nadie en la familia o en SARRC sabe quién es quién. Este diseño protege contra lo que se conoce como el efecto placebo, que se percibe el progreso como resultado de la mera participación en un ensayo. Hay problemas causados por los efectos placebo y este diseño nos ayuda a identificar sólo un progreso genuino. Muchos de estos ensayos también tienen un componente de etiqueta abierta, lo que significa que después del ensayo ciego, todos los sujetos se les da la oportunidad de estar en el medicamento. Por supuesto, un control cuidadoso continúa durante esa parte del estudio también. El coordinador del estudio en SARRC puede discutir el ensayo y ayudarle a decidir si es adecuado para usted.
Research Update

The Colonel Harland D. Sanders Center for Autism Studies

2012 is shaping up to be an exciting year for SARRC’s research team starting with the grand opening of the Colonel Harland D. Sanders Center for Autism Studies (see cover story on page 18). The relocation and expansion will better accommodate SARRC’s exceptional track record of productivity on genetic studies and pharmaceutical trials. The co-location of our Vocational & Life Skills Academy within the Sanders Center will facilitate research on the ever-increasing number of young adults and adults living with autism, a vastly under-studied and critically important segment of the population.

Current Clinical Trials

SARRC partners with several leading pharmaceutical companies to bring to Arizona cutting-edge clinical trials dedicated to the treatment of autism. Forest Research Institute and Seaside Therapeutics are each investigating medications that target core symptoms of autism. For more information about any of SARRC’s research studies, please contact Sharman Ober-Reynolds, MSN, at (602) 218-8225.

What’s New?

While SARRC continues to focus primarily on autism spectrum disorders, the new Sanders Center supports growth and allows us to include studies on related disorders. Fragile X syndrome is a genetic condition and a known cause of autism. The research on this disorder has significant implications for autism and some companies that are running trials in Fragile X are also running similar trials in autism. Seaside Therapeutics, Novartis and Roche are actively conducting studies at SARRC. To learn more about Fragile X and SARRC, please contact Sajitha Puthalth at (602) 218-8195 or Amanda Akdere at (480) 603-3285.

ThinkAsperger’s®

SARRC is committed to creating awareness and improving early detection of Asperger’s Disorder. Through our educational symposiums and Physician Outreach Program we are shifting a trend and getting educational and medical professionals to “ThinkAsperger’s” when they see a child whose social functioning is significantly behind their peers. We are currently validating the DAVE (Detecting Asperger’s Very Early) Screening Questionnaire in schools across the Valley. Once validated, this questionnaire will present teachers with a valuable tool that will indicate a need for a full evaluation for autism spectrum disorder. If your school would like to participate in this study, please contact Christopher Smith, PhD, at (602) 218-892 for more information.

Genetic Research

SARRC continues to collaborate with the Translational Genomics Research Institute (TGen) by recruiting, assessing and collecting blood samples from individuals with autism who participate in SARRC programs. Recognizing the need for sample sizes in the tens of thousands for genetic studies, these data and samples are contributed to the Autism Genetic Resource Exchange, an international repository that shares information with researchers who are investigating the genetics of autism around the world. SARRC is currently one of the most active and leading contributors of data to this effort. To learn more about how your family can participate, contact Janet Kirwan, RN, at (602) 218-8212.
The American Psychiatric Association (APA) is revising the Diagnostic Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) and it is scheduled for release in 2014. An individual’s symptom presentation cannot always be captured and, as a result, the proverbial gray area is created. Revisions are an attempt to reduce that gray area. Of particular concern in the latest revision are the changes to the section on pervasive developmental disorders. Asperger’s Disorder is no longer included as a distinct disorder. Does this mean the APA no longer considers people with Asperger’s Disorder as individuals who need support?

It is true that Asperger’s Disorder will no longer be a distinct part of the DSM, but what many fail to recognize is that Autistic Disorder is no longer in the manual either. Furthermore, Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) will also be excluded. All three disorders are being replaced with one diagnostic classification called Autism Spectrum Disorder. While the DSM-IV attempted to draw clear-cut lines among the three disorders, the lines were instead fuzzy. To many professionals, this change makes a lot of sense because for years they have referred to all three disorders as the autism spectrum.

The panel of experts who assembled to revise the criteria did not do so based on conjecture. Instead, they collected data to support the assertion that differentiating one from another carries very little meaning. They contacted the leading diagnostic centers from around the country and asked for the number of clients diagnosed in each of the three categories. If the diagnostic categories were meaningful there should be reasonable consistency across sites. For example, if the expected rates are 60 percent Autistic Disorder, 35 percent Asperger’s Disorder, and 5 percent PDD-NOS, those rates should be similar at each of the centers. The investigation found the exact opposite.

Some centers diagnosed mostly PDD-NOS, while others diagnosed mostly Autistic Disorder. The rate of Asperger’s fluctuated dramatically. There was much better agreement among centers on the rates of all three diagnoses combined. These results gave the committee the information needed to revise the criteria and create a better diagnosis of autism. So people with Asperger’s are not cast out into a void, but are now officially and more meaningfully reclassified as having Autism Spectrum Disorder.

Another criticism of the revised criteria is that some individuals who currently meet criteria for an Autism Spectrum Disorder will no longer meet criteria and thus be denied services. A study conducted recently by Dr. Fred Volkmar, an autism researcher at Yale University, suggested that a significant percentage of people who were diagnosed with autism more than 30 years ago would not meet the new criteria. While the authors of that study should be commended for attempting an empirical investigation to address this concern, the results are only as good as the data. Thirty years ago, diagnosticians would not have collected nearly the depth and breadth of information needed to diagnose an Autism Spectrum Disorder today, so the information needed to meet the new criteria may not have been present in the older assessments. Indeed the opposite might be true — by including individuals with Asperger’s into the ASD diagnostic rubric, many individuals might become eligible for state and insurance plans for services heretofore denied them.

Nonetheless, the concern that people who need services might be denied under the new criteria for autism should not be taken lightly. It is a question best investigated in a prospective study. While it is true the criteria are phrased and grouped differently, the essence of the clinical criteria for understanding and diagnosing Autism Spectrum Disorder is well captured. One particularly important feature retained from the previous criteria has remained — the symptoms together must limit and impair everyday functioning. That is, if an individual has these symptoms and is not functioning as well as peers, chances are that person would continue to meet criteria for the disorder and will indeed qualify for services.
For more than 15 years, Bill Karny has scoured the United States for the best pediatric health institutions. As a volunteer and now president of the Colonel Harland D. Sanders Foundation, he has what he would call a very fortunate mission — discovering institutions dedicated to making a difference in lives and then supporting them financially through the Sanders Foundation’s invitation-only grant process.

But this work is not how Karny came to know the Southwest Autism Research & Resource Center (SARRC).

Karny first learned of the Phoenix-based autism organization the way most people do. It started with a diagnosis of autism for his granddaughter, Charlotte, now 8 years old. Then came a phone call to Denise D. Resnik, SARRC co-founder. The conversation lasted 45 minutes, and during the call Karny was simply an overwhelmed grandparent desperately in need of answers, and Resnik was a caring voice eager to guide and full of patience and understanding.

“She had no idea who I was; I was just a grandparent, and I was frightened,” Karny recalls.

A year later, Karny paid a visit to SARRC, this time vetting it as a possible recipient of the Sanders Foundation’s $1 million grant. What he discovered was a place that picked right up where his phone conversation with Resnik a year earlier left off.

“I have been doing this as a volunteer since 1996, and I have never seen a place so well run,” Karny says. “From their use of funds to the dedication of the personnel — SARRC is just one of the best vertically integrated autism organizations in North America. They follow families, from diagnosis to adulthood. They are truly people driven.”

And the organization’s approach to research, which is where SARRC was hoping to apply Foundation funds, was no different.

**PLANTING A SEED**

SARRC was officially awarded the $1 million grant from the Canada-based Sanders Foundation in May 2011, creating the Colonel Harland D. Sanders Center for Autism Studies. This new center also serves as home to SARRC’s Vocational & Life Skills Academy at 2225 N. 16th St. in Phoenix. The Sanders grant made it possible for SARRC to purchase the building, renovate and ultimately relocate their vital research work to an area more suited to the intricate family-based studies being undertaken.

The Sanders Foundation name and support sheds a hefty spotlight on the critical need to advance autism research, especially in the face of its aging population. Of the 1.5 million Americans diagnosed with an autism spectrum disorder, 80 percent are under the age of 22. With this new, expanded facility and the professionals that staff it, SARRC aims to have a greater impact on autism and quality of life concerns by furthering pharmaceutical and therapeutic research.

Among the many studies underway, the research...
Reid Trice, 16, takes part in a Fragile X trial at the Colonel Harland D. Sanders Center for Autism Studies.
center is currently involved in nationally sponsored pharmaceutical trials that address the impact of specific medications on social functions and other core symptoms of autism. One study specifically looks at individuals affected by Fragile X syndrome, a genetic condition that often presents with symptoms of autism and intellectual disability, along with behavioral and learning challenges. SARRC has served as an ideal hub for these types of studies thanks to its widespread reach to families and highly regarded reputation. The organization’s researchers are hopeful that the discoveries made through this study may help carve new paths for autism treatments.

“These children are growing up,” Smith says. “They are moving beyond a system that no longer can meet their needs. But the benefit of conducting this research at SARRC is that we are able to touch adolescents and adults through our cutting-edge programs that support learning and development for adults with autism, programs that focus on a better quality of life.”

WAtChIng iT GROW

It is exactly this hope for a better life — for their own children as well as the generations to come — that drives Sara Trice and her family members to travel more than 400 miles from Albuquerque to Phoenix every two weeks.

Trice’s family is part of the Fragile X drug trials taking place at SARRC. She joins her granddaughter and grandson, both who are diagnosed with Fragile X, during their whirlwind trips to the Valley. Her family is a unique fit, she says, because two of her four children and two of her grandchildren, Reid and Bethany, have been diagnosed.

“We get up early in the morning and run to catch an airplane just so we can get to the research center by 9 a.m. for the trials,” says the 75-year-old Trice. “But when we get there, man, it’s like coming home. We are with people who really understand.”

The trials are double-blind studies. And though Trice doesn’t know what form of the drug her
grandchildren are on, she says she has noticed a difference in confidence and communication.

Elizabeth Ramey, Sara’s daughter and Reid’s mother, says she, too, has seen positive social behavior changes in her son, who is now 16. But whether Reid was given an active drug or not, she says simply taking part in a vital study like this is an opportunity she could never pass up.

“It’s true, you do something like this and you hope it can help your child,” Ramey says. “My life is spent trying to make his better. And I’m not going to be here forever, so I need to do what I can now. But if this research doesn’t benefit us, it may perhaps benefit thousands of others.”

This desire to fight for your own children, but also make the road just a little easier to travel down for the next family, is a common thread among the thousands of families who pass through SARRC. And Bill Karny knows that feeling as well as anyone. While his organization has helped dozens of healthcare institutions over the years to make some powerful changes in the lives of others, this grant award in particular is just a bit more personal.

“Unless you have the diagnosis, this incredible shock to your system, it’s hard to describe the fear that goes through you,” he says. “And when you’ve gone through this as a family, you know… you just know, you can make it better for others.”

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**PHARMACEUTICAL RESEARCH:**
Investigating medications for language (Secretin), gastrointestinal dysfunction (Oral Human Gammaglobulin), irritability (Risperidone, Aripiprazole), repetitive behaviors (Fluoxetine), social communication impairments (Mementine, STX209), global functioning (LUMINENZ-AT™) and Fragile X (STX209, AFQ056).

**GENETIC RESEARCH:**
Searching for autism genes and proteins with the Translational Genomics Research Institute (100 Boys Case-Control Study, Family/Genetic Study of Autism). Significant contributors of data to the Autism Genetic Research Exchange, a national repository of information from families that is designed to expedite genetic research in autism.

**CLINICAL RESEARCH:**
Investigating methods for early detection of Asperger’s Disorder (ThinkAsperger’s®, Validating the DAVE Screening Questionnaire) and the effects of providing support via the Internet to parents (Remote Parent Training).
Tallulah Anderson loved her toy animals. But she couldn’t say any of the animals’ names. For example, monkey was gibba. And no matter how hard her parents tried to teach her the correct word, she continued to say gibba.

In August of 2010 — five months after her autism diagnosis — Tallulah’s parents enrolled her in a research study at SARRC to help improve her communication skills.

**The Approach**

The goal of the study, which ran from 2009 through 2011, was to examine the effectiveness of telemedicine, explains Alexis Boglio, MA, BCBA, clinical supervisor for SARRC’s Remote Program & Telemedicine Services.

A partial replication of a study from University of California, Santa Barbara, the study was funded by the Organization for Autism Research (OAR). While the study is now closed, the Remote Program that it inspired continues.

“The program begins with a 25-hour, weeklong intensive training,” Boglio says. “It’s one-on-one training where each family has their own clinician. Parents play with their child for the full 25 hours and receive constant feedback and coaching.”

The goal, she says, is to help parents learn how to target their child’s functional verbal communication using the principles of Pivotal Response Training (PRT) during natural interactions. Then when families return to their homes, they have the skills needed to continue to work with their child using the methods they learned during training.

Some families will use an online interface to upload videos from home. The clinician reviews the videos and provides ongoing feedback.

“Families who come through...
the program are walking away with phenomenal skills and are able to implement an intervention that will continue to impact their child’s habilitation,” Boglio says.

The training doesn’t have to be exclusively held on SARRC’s campus, Boglio adds.

“We can go to the park or to the museum,” she says. “It’s about keeping the child interested and motivated.”

**Tallulah’s Experience**

Tallulah’s mom, Jen Turrell, saw the benefit. The family lives on a cattle ranch in Flagstaff, where autism resources are scarce, and they saw the Remote Program as an opportunity. Tallulah was 3 years old when they first went to SARRC.

“They helped us find language opportunities using Tallulah’s interests,” Turrell says. “Early on, she said few words. Alex gave us guidance on talking to Tallulah. We saw her pronunciation improve, and by the end, she was saying monkey instead of gibba.”

This kind of progress isn’t unusual, Boglio says.

“The impact we have in a week is dramatic. The kids will often have their first word here,” she says. “And it’s the parents who created that change in their child. That is an empowering feeling for many of the parents we have worked with.”

“It’s a lot of work, but the good news is that it doesn’t feel like work to Tallulah.

“PRT is really about sitting back and watching your child and figuring out what truly motivates them,” Turrell says. “You’re modeling and teaching language. But to her, it’s just playing.”

Today, about 18 months after the first training session, Tallulah can say the names of animals consistently and has learned some food and drink words. It gives Turrell and her husband hope that Tallulah will continue to improve her communication skills.

“Like being able to talk with peers at school,” Turrell says. “She used to never look at anyone when she’d speak. So, we’re working more on communications skills and play skills. She’s starting kindergarten in the fall, and we want her to be able to make friends.”

**Paying for Training**

Turrell, who serves on the board of the Flagstaff chapter of the Autism Society of America, has learned a lot over the past couple years — including how to take advantage of her state-provided HBB/HBM hours. In fact, she’s been able to use those hours in the Remote Program to bring Tallulah’s team of habilitators from the Flagstaff area with her to SARRC to learn how to implement PRT with her daughter.

For Turrell and her family, it’s been worth it.

“The program gives you things you can do throughout the day, which is important, especially if you don’t have other support in your area,” she says. “It’s hard for people to take the week off, but every time we’ve gone to SARRC, we’ve had major breakthroughs.”

Gila River Indian Community Provides Grant

For families who live in rural areas or on military bases, there are unique challenges.

“For families who have limited access to qualified therapists, SARRC’s Remote Program can help parents learn how to work with their child, target communication skills and continue to target those skills at home,” says Alexis Boglio, MA, BCBA, clinical supervisor for SARRC’s Remote Program & Telemedicine Services.

That’s why the Gila River Indian Community recently provided SARRC with a $125,000 grant for the Remote Program. The grant will provide training and follow-up services for 50 families who meet the requirements. Families must live in rural areas or have a member in the military to be considered for coverage under the grant.

Those selected will receive the weeklong intensive training as well as follow-ups through the program. For more information, contact Alexis Boglio, MA, BCBA, clinical supervisor of Remote Program & Telemedicine Services at SARRC, at 602-218-8198.
Although originally booked for an hour-long observation session, it took the public school psychologist only 15 minutes to determine the fate of 5-year-old Bodie Bernosky: he was fit to attend a general education kindergarten classroom. Not only that – she said Bodie did not belong in a self-contained autism classroom.

Just three years earlier, when Cori and Greg Bernosky brought their then non-verbal toddler to SARRC’s Community School, such a positive evaluation was hard to fathom. But what was once “against the odds” for a child on the autism spectrum came true last August, when Bodie made it to his first day of kindergarten alongside typically developing children. Today, Cori says he’s thriving.

“Sending him off the first day was terrifying for me. The bus pulled up and all my fears set in,” she says. “But because of all the work SARRC’s Community School did with him, he jumped on the bus and didn’t look back.”

Setting the Stage for Kindergarten: Bodie’s Story

With classes comprised of typically developing children and those on the autism spectrum, SARRC’s Community School is aimed at helping kids in the toddler, preschool and pre-kindergarten classrooms improve their social communication, behavior and development. The program uses Pivotal Response Treatment (PRT) to target children’s motivation and ability to respond, preparing them for kindergarten.

SARRC Community School Director Rachel McIntosh, MA, BCBA, attributes the program’s success...
to its mix of children. Unlike self-contained autism classrooms, kids here have the benefit of being able to forge relationships with those who don’t share the same struggles. Behavioral interventions are practiced and applied in a typical environment.

“Our clinicians teach everything systematically,” she explains. “In the world of autism, you aim for the child to acquire those skills without direct instruction, encouraging them to learn from the environment and their peers to fly on their own. The Community School makes that possible.”

When Bodie arrived at the Community School at age 2, his total language score ranked in the 1st percentile – he could only make sounds. During games and activities, he wouldn’t interact with his peers. Today, his language score is normal for his age group. More importantly, he’s making friends with classmates who do not have autism.

“I used to wonder if he’d be by himself on the playground, but I know that’s not the case,” Bernosky says. “Without the Community School, Bodie wouldn’t be in the same stratosphere he’s in today.”

Widening the Scope of Impact: Levi’s Story

Turns out, children on the autism spectrum aren’t the only ones reaping the benefits from this innovative program. Many of the typically developing children who attend are of limited means, and would not otherwise be exposed to such a high-quality, structured early childhood environment.

It’s what SARRC Clinical Services Director and Vice President Daniel Openden, PhD, BCBA-D, calls “the ultimate win-win situation.”

“These are kids who live in poverty and often don’t have much structure at home,” he explains. “They benefit from the Community School experience, and our program doesn’t work without them.”

A single mother struggling to make ends meet, Katie Abbitt says her son Levi — who does not have autism — instantly responded to the abundance of attention when he started at the Community School as an 18-month-old. With a student-teacher ratio of 3:1, each child is guaranteed frequent interaction with a highly trained teacher every day.

“All my friends noticed how smart and social he became,” Abbitt says. “In a regular childcare setting they don’t utilize the same behavioral models as SARRC to help with tantrums and acting out. Whenever I’ve had an issue with anything, they’ve come in with a plan and an intervention.”

The data from Levi’s enrollment show lagging communication skills and disruptive behavior – issues never addressed in previous childcare settings, and a load too heavy for Abbitt to carry alone. Thanks to a scholarship through First Things First of Arizona, attendance at the Community School was made possible – changing two lives at once.

“For me, it was a huge blessing,” Abbitt says. “I suddenly had the time to return to school and pick up extra work shifts to improve our financial situation. I’m now eligible for a higher paying job.”

As for Levi, at 3 years old, his total language score now ranks in the 99th percentile – above normal for his age group. Katie’s certain he’ll have a “one up” when he gets to kindergarten.

Openden sees the benefit on an even broader stage.

“This is a classic example of how investment in autism research and services is being leveraged to benefit children without disabilities, and in this case, children from underprivileged backgrounds,” he says.

Successful Inclusion through Ongoing Support

Few people know Bodie Bernosky as well as SARRC Clinical Interventionist III and former Community School teacher, Megan Bailey. She’s worked closely with him from the start, personally helping him make huge strides over the years.

That’s why for Bodie and other Community School graduates on the autism spectrum, Bailey remains involved when they go into the regular school system. When Bodie started kindergarten last August, Bailey visited the classroom twice a week to ensure he was adapting well.

“At first Bodie needed help staying on task,” she explains. “My role was to help the public school teachers and aides use prompting and reinforcement techniques to improve his communicative, social and academic behaviors.”

Thanks to her close connection to Bodie, Bailey can provide his teachers with tried and true behavioral strategies for any issues that may arise. Though she has reduced the frequency of her visits to Bodie’s school in recent months, Bailey continues to visit the Bernosky household once a week to work with Bodie and his parents, Cori and Greg, on a similar mission.

“The continuity of care since graduating from the Community School has been amazing and I think that’s been the key to Bodie’s success,” Cori says.
Ask 29-year-old Frank Ortiz how he likes his job at Alliance Beverage in Phoenix and he'll give you his standard, cheerful response almost every time: “I’m here to work and I’m just doing the best I can.”

While Frank’s words are straight to the point, the smile on his face goes much further – providing a hearty dose of optimism to an issue of huge focus for SARRC and young adults with autism throughout Arizona.

Nationally, 90 percent of adults with autism today are unemployed. With the rate of autism in Arizona now at one in 64, and 80 percent of those diagnosed under age 22, SARRC’s Vocational & Life Skills Academy is working hard to address what some refer

Model Employee
Adult with autism finds professional success through SARRC’s Employment Services program

By Phil Stuart
to as “the tidal wave coming our way.” Frank’s recent employment is a testament to the program’s success.

In some respects, Frank is just like any other night-shift employee at Alliance Beverage. Since his start last October, Frank has devoted many hours into the hefty role of loading delivery trucks for the company’s statewide liquor distribution services. However, Frank has surpassed all expectations. Managers and shift supervisors alike confirm, despite the challenges of his disability, Frank’s autism has turned out to be a real asset.

“Talk about an exemplary employee,” says Jared Duda, Alliance Beverage warehouse manager. “Frank gets here prior to his shift starting, hasn’t missed a single day of work, is always busy, and stays until after the bell rings to go home. He wants direction, he wants to know what his next task is, and then he’s after it.”

SARRC’s Employment Services program has provided placement for Frank and more than 65 percent of the program’s 150 adults since 2009. Erin Onacki, SARRC Employment Services coordinator and Frank’s job coach, explains why many employers find tremendous benefit from partnering with SARRC and hiring individuals with autism.

“In many cases, our adults are rule-driven, detail-oriented, dedicated workers committed to doing things according to process,” she says. “We’ve had amazing success with clients obtaining meaningful jobs they love and retaining those jobs long after.”

Thanks to Onacki, integration into life at Alliance Beverage was seamless. Onacki spent two weeks on site at Alliance prior to Frank’s arrival, learning the ropes, understanding the ins-and-outs of the job, educating his managers on autism and effective communication techniques, and even implementing visual flow charts to assist Frank in completing his tasks.

Within a few short months, Frank was promoted from part-time to full-time work at Alliance. His performance ratings are on par with employees who’ve worked with the company for more than two decades. Frank now earns a steady paycheck, receives full benefits and has a healthy dose of self-esteem.

“This program helps put our adults in the driver’s seat of their own lives,” Onacki says. “Employers are able to appreciate their ability, not their disability. That’s a huge stride forward for our entire community.”

Brighter Futures for Teens, Adults with Autism

Employment Services isn’t the only way SARRC’s Vocational & Life Skills Academy creates brighter futures for young adults with autism.

Beneficial Beans ™, the gourmet coffee venture that started in 2010 to create awareness about autism and sustainable products – all while providing employment for SARRC clients – is taking business to the next level. This spring welcomes the grand opening of the Beneficial Beans Café at the Scottsdale Civic Center Library, which will increase employment opportunities and professional training for adults with autism.

“We’re creating unique and groundbreaking programs,” explains SARRC President Jeri Kendle. “In the days of dwindling state and federal funds, particularly for nonprofits and adults with disabilities, we’re thinking more entrepreneurially – and it’s paying off.”

SARRC teenagers are also volunteering alongside their peer mentors at more than 30 different nonprofits, from shelters and food banks to libraries and community gardens, as part of the ongoing CommunityWorks® program. So far, they’ve provided more than 25,000 service hours to organizations around the Valley.

“The volunteerism enables our teenagers to form ties with organizations, sample different jobs and build skills that pave the way for opportunities in adulthood,” Kendle says.

SARRC’s success with the CommunityWorks® model has recently led a group in Calgary, Canada, to license the program and follow suit.

Other new additions to the Vocational & Life Skills Academy include sex education classes for teenagers, as well as “Project Launch,” an 11-week series on basic life skills ranging from budgeting and bill paying, to setting employment goals, navigating government services and increasing self-advocacy. For a complete schedule of classes and services please visit www.autismcenter.org.
In an Arkansas classroom, a 9-year-old student with an autism spectrum disorder (ASD) was becoming physically aggressive to self and staff, causing constant classroom disruptions. Amanda*, his paraprofessional educator, struggled to decrease his problem behavior and increase his appropriate behavior. Frustrated, she knew there had to be a better way to interact with her student but she wasn’t sure what to do.

Fortunately for Amanda, Arkansas’ Department of Special Education has a nine-year relationship with SARRC and its education and training program. More than 300 teachers, therapists, paraprofessionals, administrators and others who work with students diagnosed with ASDs have been trained in evidence-based intervention techniques based on the principles of Applied Behavior Analysis (ABA).

Ultimately, the success of the program lies in the effectiveness of participants to take what they’ve learned and use it immediately in schools, at home or in a community setting.

“We want to build capacity through best practices in professional development, so participants can better support individuals to develop functional skills,” says Sheri S. Dollin, M.Ed., education and training manager. “Schools can create sustainable programs to benefit students with ASDs, their peers and staff. We fully believe that with high-quality training, schools can effectively produce positive outcomes for students.”

In the fall of 2011, SARRC received a grant from Hawaii’s Department of Education to build capacity in its schools for students with ASDs and related disorders. Through professional development training, direct consultation and online coaching, educators in the island state are already seeing positive student outcomes.

“These states recognize the importance and cost-effectiveness of having highly trained staff in order to provide effective educational programming for children with autism spectrum disorders,” says Dr. Daniel Openden, SARRC vice president and clinical services director. “We’re happy to partner with states that are committed to building internal capacity to serve children and adolescents with ASDs in the classroom. By focusing on training others to implement the interventions we provide daily for Arizona families,
SARRC offers a variety of education and training options to best deliver programming to interested parties. Some examples include:

**ONE-DAY KNOWLEDGE-BASED TRAININGS**
- Autism Spectrum Disorders
- FRIEND Program
- Discrete Trial Teaching
- Pivotal Response Treatment

**INTENSIVE SKILL-BASED HANDS-ON TRAINING**
- Pivotal Response Treatment
- Discrete Trial Teaching
- Autism Diagnostic Interview, Revised (ADI-R)
- Autism Diagnostic Observation Schedule (ADOS)

Participants can receive a certificate of attendance for professional development. Other training programs are available to meet a variety of needs. Contact Sheri S. Dollin, M. Ed., at sdollin@autismcenter.org for more information.

* Name has been changed to protect privacy.

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Photos courtesy of Dave Schibel
For five years, Autism Speaks and SARRC have partnered to host the Valley’s largest autism awareness walk at Tempe Beach Park. And, although the walk has grown substantially from 2,300 walkers in 2007 to more than 15,000 participants in 2011, one thing remains true – none of it would be possible without the hard work and dedication of our volunteer walk committee!

In 2011, the walk came full circle, when longtime walk committee volunteers and parents Lynn and Neil Balter, who have 8-year-old twins, one of whom has autism, stepped up to chair the event. Their contagious passion and tireless commitment to help fun autism research and resources to support families was inspiring.

In 2011, the walk raised $1.7 million, includes 15,000 participants.
Left: More than 15,000 walkers cruise along Tempe Town Lake during the 2011 Walk Now for Autism Speaks.

Inset: Lynn and Neil Balter pose with Al Molina (right) at the thank-you reception for the Walk, which was hosted by the Molinas. The walk committee presented the Balters with a Drum Major’s hat and baton as a thank you for their leadership.

Our heartfelt thanks to Doug & Cindy Sanders and the entire Sprouts Farmers Market family for supporting the Arizona Walk Now for Autism Speaks and SARRC!

Special thanks to all of Sprouts’ customers, vendor partners and friends for HELPING RAISE OVER $1.6 MILLION FOR THE 2011 WALK!

My decision to take a stand for autism is twofold. I believe we all have a responsibility to seek out ways to improve the quality of life for those around us. My wife of 24 years, Lisa, and I are blessed with three healthy boys – our oldest attends college at University of Arizona, and our twin boys are high school sophomores. I feel we were remarkably fortunate, given the startling high statistics of boys born with autism. At the same time, I cannot help but feel a true sense of urgency to uncover the causes of autism and to develop resources that will help support families in our community affected by the disorder.

My first introduction to autism was in early 2006, when some friends approached me to help fundraise for the creation of a vocational and life skills center to help young adults and adults affected by autism. The Phoenix community rallied to support SARRC, raising upwards of $500,000 to make the Vocational & Life Skills Academy a reality. At that time, roughly one in 166 children nationwide were being diagnosed with autism – a statistic that hit home hard when my very close friends learned that their then-2-year-old son, Jack, was diagnosed with the disorder. Today the incidence is startling, one in 64 in Arizona.

This year, as walk chairman, my hope is to continue to engage family walk teams and to encourage more participation from high school and college students, ensuring that our future generation of community leaders will become ambassadors of autism. I look forward to walking with you!
S echoing on the Arizona Diamondbacks as they take on the Atlanta Braves at the 5th Annual Autism Awareness Game at Chase Field. $5 of every ticket sold will benefit Autism Speaks and SARRC. Reserve your tickets today by calling (602) 340-8717, ext. 1460.

**Date:** Fri., April 20  
**Time:** 6:40 p.m. start; post-game fireworks, weather permitting  
**Place:** Chase Field, 401 E. Jefferson St., Phoenix  
**Cost:** Single tickets range from $17-$42, depending on location

**Sutton’s Strokes for Little Folks Golf Tournament**

The 7th Annual Sutton’s Strokes for Little Folks golf tournament benefitting SARRC will be held at the Arizona Grand Resort. This tournament will once again provide golfers of all skill levels with great food, laughter, golf and fabulous music. For additional details and to register please visit www.suttongolf.org.

**Date:** Thurs., May 10  
**Time:** Check-in time is 10:30-11:30 a.m.  
**Place:** Arizona Grand Resort, 7777 S. Point Parkway, Phoenix

**2012 Arizona Walk Now for Autism Speaks**

Join Autism Speaks and SARRC for the 2012 Arizona Walk Now for Autism Speaks happening on Sun., Oct. 28, at Tempe Beach Park. More than 15,000 participants are expected to participate this year. The family-friendly walk is free to attend and includes live entertainment, a kids’ zone featuring dozens of activities and an autism resource fair with more than 50 community resources. For more information about how you can support the walk, details on how to form a walk team and more, visit www.walknowforautismspeaks.org/arizona.

**Date:** Sun., Oct. 28  
**Time:** 8 a.m. registration; 9:45 a.m. walk start  
**Place:** Tempe Beach Park, 80 W. Rio Salado Parkway

**The FRIEND Program**

This training offers an overview of the FRIEND® program, an inclusive social-skills program for preschool-12th grade students that provides increased awareness of ASDs, and information on how to create learning opportunities for individuals with ASDs to engage appropriately with typical peers in the natural setting at school during lunch and recess. Participants will develop an understanding of learning challenges that may impact social interactions with peers. A discussion of how to implement the lunch and playground program will be reviewed. Innovative materials will be shared to include the FRIEND program manual, children’s books Wings of Ephoh and I’m Here, DVDs, educator activity guides, informational tips useful for peer sensitivity training and appropriate strategies for facilitating social interactions with school-age students.

**Date:** Fri., June 15  
**Time:** 9 a.m.-3 p.m.  
**Place:** SARRC Vocational & Life Skills Academy, 2225 N. 16th St., Phoenix  
**Cost:** $50 per attendee
Support Groups

Grandparents Group
The Grandparents Group focuses on educating and supporting grandparents of children with autism and presents the latest news and research in the field. The group meets once a month October through May. New grandparents are welcome to come at 9 a.m. for a meet-and-greet tour of SARRC.

Dates: May 4, Oct. 19 and Nov. 9
Time: 10-11:30 a.m.
Place: SARRC Campus for Exceptional Children, 300 N. 18th St., Phoenix
RSVP: (602) 218-8203

Lunch & Learn: Know Your Educational Rights Under the Law
Guest presenters Hope N. Kirsch, Esq., and Lori Kirsch-Goodwin, Esq., will begin with an overview of the federal special education law, “Individuals with Disabilities Education Improvement Act” (IDEIA), state law and notable case law decisions interpreting the legislation. The presentation will also address:

- The rights of students with special needs in public and charter schools
- Whether a student is entitled to IDEIA protections at private schools
- Requirements of FAPE (free and appropriate public education)
- LRE (least restrictive environments)
- Evaluations and reevaluations
- Placement
- The IEP itself
- Timeline and discipline procedures
- Other laws (No Child Left Behind, FERPA)

Date: Mon., July 23
Time: Noon-1 p.m.
Place: SARRC Campus for Exceptional Children, 300 N. 18th St., Phoenix
Cost: $15 per person

West Valley Autism Parents Support Group
Join mothers of children with autism for a night out. Share your experiences, make new friends and learn something new. Contact Shelly Vinsant for more information at shellyvin@cox.net.

Dates: Second Monday of every month
Time: 7-9 p.m.
Place: New Life Community Church, 8155 W. Thunderbird Road, Peoria
Cost: Free

East Valley Autism Network (EVAN)
EVAN is a parent-led support group providing hope, resources, information and support for families with children on the autism spectrum. EVAN welcomes all families who would like to network and help each other get the services and education children with ASDs need. Contact Melissa at melissavanhook@hotmail.com for additional information and to RSVP.

Dates: Third Tuesday of every month
Time: 7-9 p.m.
Place: Varies

For a complete list of SARRC’s workshops and trainings, visit autismcenter.org and click on calendar. To register, call (480) 603-3283 or e-mail training@autismcenter.org.
## Programs

### JumpStart®

JumpStart teaches parents about the characteristics of ASDs and covers a variety of important topics, including improving social communication, reducing problem behaviors, addressing concerns surrounding sleep and feeding, accessing state services and much more. JumpStart uses ABA-based interventions, including Pivotal Response Treatment and Discrete Trial Teaching. This five-week series is open to parents of children up to age 6, and includes discussion groups and hands-on training led by SARRC’s team of specialists. The entire JumpStart program is also offered in Spanish for monolingual Spanish-speaking families.

### Community School

The SARRC Community School toddler, preschool and pre-K classrooms include children at risk for or diagnosed with autism along with typically developing children in a naturalistic classroom environment. The school promotes language and social development while providing positive supports to minimize behaviors that interfere with learning. Diagnosed children receive additional one-to-one interventions throughout the day that focus on the development of cognitive, motor, self-help, communication and social-emotional skills. Structured activities are available to all the children throughout the day and are specifically designed to foster engagement and social interaction. All-day care is available for typically developing children.

### Comprehensive Home-Based Behavioral Program

SARRC’s comprehensive behavioral program is designed for families with children up to the age of 16 who are diagnosed with an ASD. The program consists of parent training and one-to-one intervention sessions provided by skilled clinicians in the family’s home and community. Sessions are highly individualized in order to incorporate the current goals of the family and child. Goals are based on the needs of the family and the child, and focus on the development of social communication, play skills, self-help skills and reductions in problem behavior.

### Home-Based Consultation

Home-based consultation is available for families with children up to the age of 13 who have been diagnosed with an ASD. Consultations are individualized for the child and family and may be provided in the family’s home, at SARRC or in the community. Consultations may include interviews with family members, direct observation of the child, development of a behavior intervention plan, training to implement the plan and ongoing follow-up as needed.

### Specialized Habilitation Services

Specialized Habilitation is available for children up to age 5 who have been diagnosed with an ASD. The program focuses on increasing the child’s social communication through correct implementation of Pivotal Response Treatment (PRT) in 16 in-home parent-training sessions. Families of children who do not qualify for state-funded Specialized Habilitation may receive these services through an affordable private-payment option or insurance coverage.

### Remote Parent Training

SARRC clinical interventionists provide parents of children with ASDs intensive training in the motivational procedures of Pivotal Response Treatment to meet each child’s individual communication, social and behavioral needs. Parents and their child meet with SARRC clinical interventionists for 5 hours each day, Monday-Friday, for a total of 25 hours. After their initial week-long training at SARRC, families return home and have the option of receiving telemedicine support from SARRC’s clinicians by sharing video over a secure internet connection, allowing SARRC clinicians to remotely provide ongoing feedback to parents as the child’s skills and needs change over time. The program is particularly useful for families living in rural/remote locations or outside of Arizona.

### Autism CommunityWorks®

CommunityWorks® is a popular program that helps youth between the ages of 13 and 18 make the transition to adulthood, higher education and/or optimum employment. This vocational training program for youth provides the opportunity for individuals with ASDs and their peer mentors to engage in volunteer work throughout their communities while developing job skills, learning to socialize and building lasting friendships.

### Vocational Opportunities for Individual Career Experiences (VOICE)

Becoming part of the economic fabric of one’s community is vital for developing a sense of pride and improving quality of life. Through VOICE, partnerships with local and national employers have been created to increase competitive employment opportunities for clients, while teaching appropriate work behaviors, building social skills and providing specialized vocational training in a structured environment. Client services include developing a vocational goal, functional assessments to identify job readiness skills, resume and job interview preparation, building natural supports at work, job shadowing opportunities, on-the-job training and ongoing job coaching, and assistance identifying and obtaining reasonable job accommodations.
Entrepreneurial Center for Special Abilities (ECSA)

ECSA provides young adults and adults with ASDs training and work opportunities that involve them in every aspect of operating a business. ECSA’s CulinaryWorks® program partners with Arizona’s most celebrated chefs in the preparing, packaging and selling of SARRC’s signature soups. It also involves them in the roasting, packaging and selling of SARRC’s own blend of coffee, Beneficial Beans™, in addition to providing competitive employment opportunities at the Beneficial Beans Café. ECSA’s Humana GardenWorks® engages individuals in developing and sustaining a revenue-producing co-op garden. Adult participants learn through hands-on gardening, sustainable landscaping and water harvesting training. They also have the opportunity to engage in product development, marketing and sales. Both ECSA programs are beneficial in building transferable skills while making connections and lasting friendships. Community members are encouraged to mentor individuals with ASDs in both programs to help them gain skills they can use to work toward financial independence.

Academy of Classes

Offering a multitude of options to help teens and adults improve social skills, prepare for employment, develop skills needed to live independently and forge honest relationships. The Academy of Classes has something for everyone and provides the flexibility to meet varied learning styles. Programs include:

- **LIFE SKILLS SERIES**: 10-week series for adults that focuses on the following targeted objectives: communication and social skills, basic budgeting and money management, managing a household, maintaining proper hygiene, preparing simple meals, utilizing public transportation and navigating the community.
- **PROJECT LAUNCH**: 11-week series for teens that focuses on self-exploration, including goal development, advocacy, career and education exploration, budgeting, relationships and social skills, and professional communication.
- **AUTISM ARTISANS**: Series of art workshops, designed to expose emerging and established artists to a variety of art mediums while learning about opportunities to develop careers through the arts.
- **MONDAY NIGHT OUT**: Fun monthly social event that provides a relaxed atmosphere to meet new people and practice social skills.
- **SOCIAL CLUBS**: Opportunities to engage in fun activities in the community while practicing social skills and meeting new people.

Transition Program

This program is rooted in Applied Behavior Analysis, an effective treatment based upon more than 50 years of scientific investigation with individuals affected by a wide range of behavioral and developmental disorders. Individualized programming is designed to increase functioning and independence, and decrease disruptive behaviors. Services include a comprehensive assessment, development of a service plan, in-home parent training, in-home one-on-one direct ABA services and quarterly progress reports. Strong emphasis is placed on teaching parents how to implement ABA-based interventions and track data to better understand their child’s behaviors and needs.
Get Connected

**Education and Training Program**

The Education and Training Program offers a range of training and activities created for families, providers, school faculty, administrators, therapeutic and medical professionals, and others living, working or with an interest in supporting an individual with an ASD. The content for trainings addresses practical knowledge and skills for implementation of interventions based on principles of Applied Behavior Analysis (ABA). This program furthers understanding of ASDs, cutting-edge research and evidence-based treatment approaches.

**Think Asperger’s®**

This outreach program is designed to educate elementary school staff and pediatricians to “Think Asperger’s” when they see subtle social impairments in very young children. If undetected, subtle social impairments may lead to more serious social deficits and a lifetime of struggle. After interviewing parents of individuals with Asperger’s, SARRC developed an educational program and screening questionnaire to help teachers and pediatricians recognize these impairments and refer for a formal evaluation. Once individuals are properly diagnosed, intervention can begin so they can have meaningful interactions, develop friendships and ultimately reach their full potential.

**FRIEND® Program**

The FRIEND program is an inclusive curriculum designed to improve social skills for school-age students with an ASD or other social challenges. Children with social challenges are taught how to appropriately engage with their peers through structure and support in the natural environment throughout the school day. Typical peers are taught strategies to assist their peers with social challenges during naturally occurring social interactions. The FRIEND program includes three components: peer sensitivity training, the FRIEND playground program and the FRIEND lunch program.

**FRIEND Summer Camp**

SARRC has partnered with the YMCA to include children with ASDs (ages 3-13) with their typically developing peers in existing YMCA summer camps. The FRIEND Summer Camp provides one-to-one facilitators to ensure that children with ASDs can successfully participate throughout the day and across structured and unstructured activities. Facilitators receive training in behavioral programming and inclusive strategies to target communication, appropriate play and social skills with peers. Children with ASDs are required to attend camp for at least one four-week session. Camp runs from 8 a.m. to 4 p.m. weekdays during the months of June and July and is offered at two YMCA locations: the Downtown Lincoln YMCA and the Scottsdale YMCA.

**School Consultation**

School-based services are provided by SARRC educational consultants to school staff and administration as requested. Through professional development trainings, school consultation and evaluation services, educational consultants provide skill-based knowledge on educating students with ASDs. Interventions and strategies taught through these services are evidence-based and applicable to all students in special and general education settings.

**Physician Outreach Program**

SARRC’s Autism Spectrum Disorders Screening Kit enables physicians to effectively screen for autism spectrum disorders during developmental checkups. The kit includes parent questionnaires, presented in English and Spanish, scoring templates and referral materials to assist with timely referrals and earlier diagnoses. Training meetings are held monthly and include all medical personnel who are interested in learning more about autism.
My son Daniel, now 19, was diagnosed with autism shortly before SARRC was founded in 1997. I always felt lucky that Daniel was among the first generation of children served by SARRC’s cutting-edge programs — from family and teen camps at Whispering Hope Ranch to life-skills and job training classes at its Vocational & Life Skills Academy.

Daniel and his peers with autism are now “young adults.” After years of challenges and gains that sometimes seemed to come at a snail’s pace, Daniel is a young man entering his prime learning years. His meltdowns, which used to occur many times a day, are now rare. He has learned techniques to manage his anxiety and can adjust to unexpected changes in his routine — changes that in the not-so-distant past would have thrown him off track for hours.

He can recite the date that every soft drink was invented and loves commercials, music and movies from the 1940s. He makes his bed, cleans the bathroom, dresses himself in the mornings and gets his own cereal. Five years ago this progress would have seemed impossible.

So… what happens next? Despite his remarkable progress, Daniel will never be able to live on his own. Daniel’s younger brother, who has served as the “older” brother for so long, will soon leave home for college. Our family is entering a new stage, which is both exciting and scary. The practical aspects of how I can provide for Daniel’s care not just for my lifetime, but for the rest of his lifetime, weigh on me.

I can still vividly recall Daniel’s younger brother announcing, years before he even entered high school, that he would not ever go away to college because he needed to stay at home to help with Daniel. Although we talked him out of this plan, the prospect of providing for Daniel’s care, now and in the future, is an ever-present reality for our family.

My vision for Daniel is that he will live as independently as possible, in a residential community setting that may well include some of the kids that have grown up alongside him in SARRC’s programs over the years. It will be a place with staff trained to work with individuals with autism, so he can continue to learn and grow. It will be a place that provides access to recreational activities and jobs out in the community. And it will be a place that other family members can visit regularly, knowing Daniel has a home where he is safe, healthy and happy.

While a place like this does not yet exist in Arizona, I have no doubt SARRC’s residential initiative will be one step ahead, paving the way to a brighter future for Daniel and his peers with autism.

Jodi Knobel Feuerhelm is the mother of two sons, including 19-year-old Daniel who was diagnosed with autism at age 3. She is also a partner with the law firm of Perkins Coie LLP in Phoenix and a member of SARRC’s Residential Advisory Committee.
A snapshot of SARRC’s scientific contributions is reflected in the numbers below. While progress is being made, we still have a long way to go toward unraveling the mysteries of this perplexing neurobiological disorder. Scientific discoveries are advancing at a more rapid pace than ever before and we’re proud to be contributing to national and international research while advancing our own self-directed clinical studies. Since our founding in 1997, SARRC remains committed to improving the quality of life for individuals living with autism and Asperger’s.

3,352
Individuals with an autism spectrum disorder entered in SARRC’s research database

10,636
Individuals, including family members and research control subjects, entered in SARRC’s research database

1,488
Blood samples collected for research

508
Diagnostic assessments completed

784
Number of individuals who have contributed to the Autism Genetic Resource Exchange (AGRE) repository

25
Pharmaceutical trials conducted at SARRC

100
Identified genes that have an association with autism, which may be responsible for 12 to 15 percent of diagnosed cases of autism

600
The estimated number of genes thought to explain all cases of autism

10,000
Individual blood samples available for autism research today

50,000
Individual blood samples needed to identify the approximately 600 genes believed to be associated with autism
WE ARE PROUD TO SUPPORT SARRC IN MAKING A WORLD OF DIFFERENCE IN THE LIVES OF INDIVIDUALS AFFECTED BY AUTISM AND THEIR FAMILIES.
Thank you to the entire team at News/Talk 92.3 KTAR and the generous Action for Autism sponsors for making your imprint on autism. For the fifth year, your tremendous leadership and vast community outreach efforts have been instrumental in educating the community about autism and generating support for vital SARRC programs.